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# ALZHEIMER'S DISEASE AND FAMILY CAREGIVING: FAMILY NETWORK CHARACTERISTICS INFLUENCING THE CAREGIVER'S PERCEPTION OF FAMILY SUPPORT

BY

©

WONITA JANZEN

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF SCIENCE

IN

FAMILY STUDIES

DEPARTMENT OF HUMAN ECOLOGY

EDMONTON, ALBERTA

FALL 1993

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DEGREE: Master of Science

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The undersigned certify they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled ALZHEIMER'S DISEASE AND FAMILY CAREGIVING: FAMILY NETWORK CHARACTERISTICS INFLUENCING THE CAREGIVER'S PERCEPTION OF FAMILY SUPPORT submitted by WONITA M. JANZEN in partial fulfilment of the requirements for the degree of MASTER OF SCIENCE in FAMILY STUDIES.

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## ABSTRACT

The impact of Alzheimer's disease is severe and far-reaching, affecting individuals, families, communities and society in general. Today, family members are the major providers of care for relatives with dementia. The term "family caregiving" has become common in both research and practice. However, this term is deceptive since one family member usually becomes the primary caregiver of the ill relative and the other family members may or may not provide support to this person.

Within the stress, social support and coping literature, perceived support has been recognized as an important aspect of the stress and coping process, although it has received limited attention in research studies. The purpose of this study was to examine the influence of family characteristics on the primary caregiver's perception of the adequacy of family support.

The study involved a secondary analysis of data from a research project examining factors leading toward institutionalization of Alzheimer's relatives by family caregivers. The sample consisted of 91 primary caregivers from the original research. A discriminant analysis was performed using eight family characteristics and three control variables to distinguish between caregivers who viewed family support to be adequate and those who viewed family support to be less than adequate to their needs.

Results indicated that four of the eight family variables contributed to the function discriminating between caregivers who perceived family support to be adequate and those who perceived family support to be less than adequate. Caregivers who viewed family support to be adequate had more family members providing help specific to caregiving, received more practical and emotional help, and had less time elapse since the date of diagnosis of Alzheimer's disease.

ACKNOWLEDGEMENTS

This author would like to express sincere appreciation and gratitude to the many people who assisted me with the completion of this thesis.

Thanks are offered to my thesis advisor, Dr. Norah Keating for her guidance and support. I would also like to thank my committee members for their suggestions and statistical advice.

Special thanks are offered to Karen Kerr, the Caring Project Coordinator, for her assistance and encouragement.

Finally, I would like to thank my husband for his constant support and encouragement, as well as editing and design assistance.

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# I. INTRODUCTION

The average age of Canadians is rising as the "baby boomers" age and as fertility rates decrease (Statistics Canada, Births and Deaths, 1986). Population aging has profound implications for the individual, the family and society because it affects income, healthcare, leisure time, labor structures, and community organization (Marshall, 1987). The impending changes to the structure of our society and economy require adjustment in the private and public sectors to adequately meet the needs of the elderly (Messinger & Powell, 1987). One of these needs may be in long term care. Schneider and Brody (1983) suggest that chronic disease will be present during more years of life as a result of people living longer.

The provision of care to the frail and ill elderly has become a major issue, both in the health and welfare realms and in research. Caregiving by informal sources, particularly family, is the primary source of assistance for the elderly in contemporary society (Chappell, 1992). In the past, family caregiving was quite commonplace, in part due to limited health care services (Keating, Kerr, Warren, Grace & Wertenberger, 1993). The modern interest in family caregiving has likely arisen from the economic implications of Canada's aging population and constraints on health care dollars (Messinger & Powell, 1987). The emphasis on family caregiving is supported by a societal belief that elders receive the best care at home and by limited health care dollars (Keating, et al., 1993).

## Background to the Problem

Alzheimer's Disease is a chronic illness "characterized by intellectual deterioration, disorganization of the personality, and functional disabilities in carrying out the tasks of daily living" (Miller & Keane, 1987). This debilitating illness occurs in approximately two percent of the population over age 60, and in over 20% of those aged 80 years and over (Health and Welfare Canada, 1984). Although Canada has one of the highest rates of institutionalization in the world, the majority of patients with dementia, particularly those with less severe symptoms, are living in the community (Robertson & Reisner, 1982). Most of the

care for people with dementia is provided by family members (Ory, Williams, Emr, et al, 1985). However, the Alzheimer's patient will only be kept in the community for as long as the family caregiver can cope with the cognitive and behavioral changes in the patient and the responsibilities of caregiving.

Although the literature often refers to "family caregiving", it is usually one family member who becomes the primary caregiver (Ory et al, 1985). This primary caregiver (henceforth referred to as the caregiver) is almost always a spouse or an adult child who is either a daughter or daughter-in-law (Niederehe & Fruge, 1984; Zarit, Reever & Bach-Peterson, 1980). Some recent studies have examined how the other family members participate in caregiving or assist the caregiver (Brody, Hoffman, Kleban & Schoonover, 1989; Lerner, Somers, Reid, Chiriboga & Tierney, 1991; Tennstedt, McKinlay & Sullivan, 1989). The participation of family members in caregiving duties or their direct help and encouragement to the caregiver may lead the caregiver to feel supported by his or her family.

Within society, the family is assumed to be a supportive environment (Hansson, Nelson, Carver, et al., 1990; Keating, et al., 1993; Pett, Caserta, Hutton & Lund, 1988). However, an individual may not always feel supported by his or her family, even though it may appear to be a supportive environment. For example, one cannot assume that a caregiver is supported by her family because she has several relatives living within the same city. She may feel supported because she receives daily assistance from these relatives, or she may feel unsupported because she has no contact with any of these relatives. For each individual, relationships and interactions with family members that lead to a feeling of support may differ (Heller & Swindle, 1985). The present study was designed to examine the relationship between certain family characteristics and the caregiver's perception of family support.

## Statement of the Problem

Social support is seen as particularly beneficial when one is experiencing a stressful situation, such as caring for an ill relative (Cohen & Willis, 1985; Given, Collins & Given, 1988; Heller & Swindle, 1983; Lazarus & Folkman, 1984). A

stressful situation may create needs for resources, which an individual, such as a caregiver, did not necessarily have before the situation occurred. For example, if the relative with Alzheimer's disease has a tendency to wander, the caregiver may need someone to watch the relative while he or she runs errands. Although stressful situations may invoke needs for many kinds resources, specific events elicit the need for specific resources (Cohen & Willis, 1985). When these resources are supplied by other people in the caregiver's environment, the caregiver may perceive the support of others to be adequate to meet the needs of the caregiving situation.

Caregivers of Alzheimer's patients are a unique population immersed in a specific situation. These people are experiencing an increase in duties and responsibilities associated with the disease that may require 24-hour attention (Robertson & Reisner, 1982). The caregiving situation is a long-term endeavor which increases in comprehensiveness due to the progressive deterioration of Alzheimer's patient. Caregivers, who are often spouses or children, are facing the imminent death of a loved one. It is in times of need when one's family may be a salient source of help or comfort (Gottlieb, 1991; Matthews & Rosner, 1988). Specific kinds of resources from family members may be necessary to meet the demands of the caregiving situation. Family social support may mediate the effects of the stressful situation only when the caregiver perceives an adequate match between the requirements of the caregiving situation and the resources received from other family members (Cohen & Willis, 1985).

For the caregiver population, the question remains as to which resources from family members lead to a perception of adequate family support? There has been little systematic research examining how family help or interactions influence the caregiver's perception of family support. Thus, the following research question was proposed: Do family network characteristics discriminate between caregivers who perceive family support to be adequate and those who perceive family support to be less than adequate?

## Justification

The fact that the majority of Alzheimer's and dementia patients are cared for at home by family members (Ory, et. al., 1985; Robertson & Reisner, 1982) suggests that there is a need to examine the resources available to these caregivers. One of the concerns of both practitioners and researchers is how to ensure that the caregiver is adequately supported. Attention often focuses on the family. There is an assumption that family networks are supportive (Pagel, Erdly & Becker, 1987), although exploration of this assumption is relatively new. The identification of family resources (ie. characteristics), such as relationships, interactions or helping behaviors, which may contribute to the caregiver's perception of support would provide additional information about family support in a caregiving situation.

Establishing the family characteristics which influence the caregiver's perception of family support is important for a number of reasons. First, this information would contribute to the body of knowledge available on family caregiving and social support by focusing on support within the family. The assumption in society and research regarding "family caregiving" may be better understood through investigation of how family members provide support to each other. Greater knowledge in this area would also benefit the efforts of formal sources of support (eg. healthcare professionals) to the family through the coordination of services with family support.

Second, examining the primary caregiver's view of the adequacy of family support to meet his or her needs may clarify the concept of support. Often "support" is assumed through measurement of more objective behaviors or interactions (Sarason, Shearin, Pierce & Sarason, 1987). However, receiving assistance or having contact with a family member is not the same as feeling supported. With the promotion of the subjective perception of support by researchers (Barrera, 1981; Heller & Swindle, 1983), asking the caregiver about how supported he or she feels may give us a more accurate picture of family support.

Third, exploring the relationship between more objective factors (eg. family characteristics) and the subjective evaluation of support adequacy could help to reaffirm or refute the assumed connection between these two concepts. Certain family characteristics or traits are assumed to be supportive (Cutrona, 1986; Sarason, et al., 1987; Stokes, 1983). Establishing a link between the family characteristics and perceived support may assist researchers and practitioners in understanding support within the family.

Finally, more knowledge of the family milieu of caregivers may benefit decision makers and practitioners in the health and welfare professions and health care systems in Canada in providing more effective and efficient service to caregivers and their families. For example, if the number of family members participating in caregiving tasks positively influences the caregiver's appraisal of the adequacy of family support, then health professionals may identify caregivers who are at risk for feeling unsupported by their family and who may require formal supports. In the long run, the caregiver's perception of adequate support may benefit the health care system financially because the Alzheimer's patient may be kept in the community for a longer period of time by a caregiver who views his or her support to be adequate to meet his or her needs within the caregiving situation. The longer the Alzheimer's relative is kept in the community, the less strain there will be on healthcare dollars.

## II. CONCEPTUAL FRAMEWORK

Much of the research on social support and caregiving has been embedded within a stress and coping framework. Social supports are believed to be particularly salient when one is dealing with a potentially stressful situation (Cohen & Willis, 1985; Marsella & Snyder, 1981; Wethington & Kessler, 1986; Wilcox, 1981). Within the context of caregiving, the caregiver's perception of social support from his or her family may be crucial to how the caregiver copes with the situation.

This chapter begins with a general discussion of the stress and coping process. This will be followed by a description of the model which provides the theoretical foundation for this thesis.

### The Stress and Coping Process

An overview of some basic premises upon which the stress and coping theories are built will precede the discussion of the model used as a framework for the present study. Three basic assumptions are relevant to the question at hand. First, individuals and families face hardships and changes in their environment as a natural aspect of life over the life cycle (McCubbin & McCubbin, 1987). Changes may be major, such as severe illness, or the loss of a loved one, or they may be daily hassles, such as dealing with an inconsiderate smoker or misplacing one's car keys. These changes can be stressful for family members (Lazarus & Folkman, 1984). With respect to the caregiving situation, taking on the role of caregiver can be a major change in a person's life. New responsibilities and tasks are associated with the caregiving situation (Killeen, 1990; Robertson & Reisner, 1982; Stoller & Puglieski, 1989). The new and demanding situation, occurring simultaneously with daily hassles (Wallsten & Snyder, 1990) can be stressful for the caregiver (Given, et al., 1988).

Second, families and individuals develop basic strengths and capabilities designed to nurture and protect the family members from major disruptions during periods of change and to foster adaptation following a major life transition (McCubbin & McCubbin, 1987). Through experience and trial-and-error, families adopt patterns of interacting which are intended to foster growth and development

of family members and the family unit. These strengths, capabilities and patterns of interaction are called resources (McCubbin & McCubbin, 1987). For the caregiver and other family members, family resources may ease the trauma of the transition to caregiving. For example, a pattern of helping behaviors may create an atmosphere of support for the caregiver.

Finally, the stress and coping process involves a cognitive perception or appraisal of the relationship between the person and the environment (Lazarus & Folkman, 1984). Stress and coping is not a stimulus-response relationship. Rather, people cognitively evaluate their situations and resources in accordance with past experience and present knowledge (Lazarus & Folkman, 1984). The resources which an individual has can influence that individual's appraisal of the resources and the situation. For example, one caregiver may perceive her family to be very supportive based on the amount of help she receives from other family members in comparison to the needs created by the situation. Another caregiver may perceive her family to be non-supportive also based on the amount of help she receives from other family members. Cognitive appraisal determines the action which an individual takes in response to stressful situations. The caregiver who perceives family support to be less than adequate to meet his or her needs may look to other sources of help, such as formal assistance.

The three premises outlined above are the foundation upon which the present study was built. First, this study involved a specific change in the lives of family members; the transition into caregiving. Second, this study examined a number of family resources which may meet the needs of the caregiver in the new situation. Finally, the present study focused on the caregiver's cognitive appraisal regarding the adequacy of family support.

## A Model of Social Support and the Coping Process

A model of social support and the coping process designed by Heller and Swindle (1983) is depicted in Figure 1. These authors propose relationships between factors in the environment and perceived social support. Their model provided a basis for the present

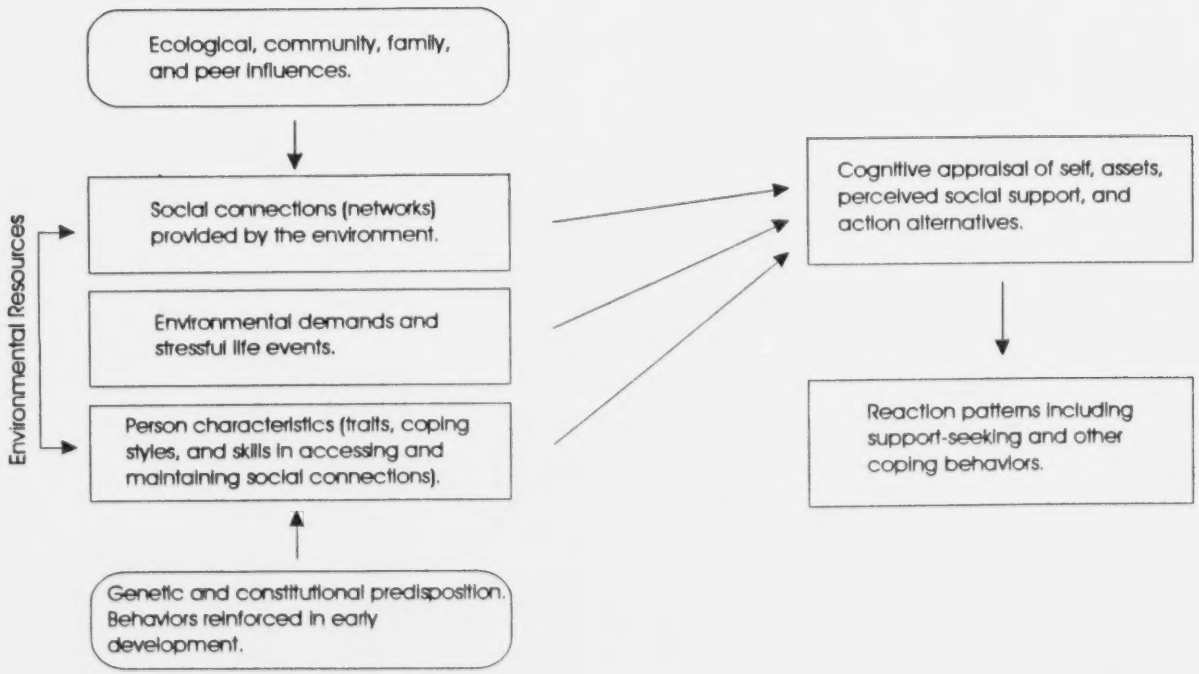
Ecological, community, family, and peer influences.
Social connections (networks) provided by the environment.
Environmental demands and stressful life events.
Person characteristics (traits, coping styles, and skills in accessing and maintaining social connections).
Genetic and constitutional predisposition. Behaviors reinforced in early development.
Environmental Resources
Cognitive appraisal of self, assets, perceived social support, and action alternatives.
Reaction patterns including support-seeking and other coping behaviors.

Figure 1. A Model of Social Support and the Coping Process (Heller & Swindle, 1983)

study which was to examine the link between factors in the environment (family characteristics) and the perception of family social support by the caregiver. A description of the main concepts and their application to the research question follows.

Environmental Demands and Stressful Events

Individuals or groups are embedded in environmental systems. The environmental systems (eg. social, biological) place demands upon the individual. Environmental demands, also referred to as stressors, are life events, transitions or changes which potentially impact upon the family or individual (McCubbin & McCubbin, 1987). These may be as extreme as natural disasters, imminence of death, severe illness, or loss of a loved one or they may be as commonplace as dealing with an inconsiderate smoker, having too many responsibilities, or having an argument with a family member (Lazarus & Folkman, 1984). Whether the environmental demand is extreme or commonplace, it generally requires the attention and action of the individual.

The environmental demands of the caregiving situation may include dealing with the behavior changes in the ill relative, adding caregiving tasks to one's daily routine and responsibility, facing the loss of a loved one, 24-hour care responsibility, reduced time for other activities, etc. (Killeen, 1990; Robertson & Reisner, 1982; Wallsten & Snyder, 1990). The caregiver must respond to these demands. One of the premises of the stress and coping theories is that the caregiver will evaluate the resources available to help him or her cope with the demands of the caregiving situation (Lazarus & Folkman, 1984; McCubbin & McCubbin, 1987). This evaluation is called appraisal.

Appraisal

In Heller and Swindle's (1983) model, cognitive appraisal is the key to the stress and coping process (see Figure 1). Cognitive appraisal is defined as "evaluative cognitive processes that intervene between the encounter and the reaction. Through the cognitive appraisal processes the person evaluates the significance of what is happening for his or her well-being" (Lazarus & Folkman,

1984, p.52). Appraisal requires a mental judgement, discrimination, and choice of activity, based largely on past experience. For example, the ill relative may begin to display physically aggressive behaviors. The caregiver may evaluate how dangerous these behaviors are to his or her well-being and may consider the options for dealing with the incidents. The situation requires that action be taken. The action the caregiver takes is based on his or her appraisal of the seriousness of the situation and the resources available to deal with the aggressive incidents.

Lazarus and Folkman (1984) describe three kinds of appraisal. Primary appraisal is conceptualized as the cognitive process through which an environmental demand is evaluated with respect to one's well-being. The demand can be appraised as 1) *irrelevant* when it carries no implication for a person's well-being; 2) *benign-positive* when the outcome of an encounter is viewed as positive, preserving or enhancing one's well-being; or 3) *stressful* when the outcome of the encounter is harm/loss, threat or challenge to one's well-being.

Secondary appraisal is conceptualized as the evaluation of the coping options which are available to deal with the situation. It takes into account the coping options available, the adequacy of the resources to accomplish what they are supposed to, and the likelihood that one can apply a particular strategy or set of strategies effectively. Coping options have also been referred to as "resources" within the stress and coping literature (Hill, 1958; McCubbin & McCubbin, 1987).

"Reappraisal refers to a changed appraisal on the basis of new information from the environment, which may resist or nourish pressures from the person, and/or information from the person's own reactions" (Lazarus & Folkman, 1984, p.38). This appraisal is feedback which may stimulate the person to reassess the initial appraisals made with regard to the environmental demand or coping reactions.

Heller and Swindle (1983) state that their model focuses on secondary appraisal. Appraisal of resources, including appraisal of self, perceived social support, and action alternatives (Figure 1), is influenced by social connections, environmental demands, and person characteristics. The appraisal of resources

in turn influences the individual's reaction to the environmental demands. Application of this model to the caregiving situation would indicate that the caregiver's social networks (including family, friends, and formal relationships) and person characteristics may influence how the caregiver perceives the support he or she is receiving from network members. The perception of support, whether viewed positively or negatively, influences how the caregiver deals with or copes with the caregiving situation. The aspect of this model which was of interest in present study was the relationship between the caregiver's family network (an environmental resource) and his or her perception of family support (appraisal). These two concepts will be further elaborated.

Environmental Resources

Within the stress and coping theories, the environment is assumed to provide resources which can be drawn upon in demanding situations (Heller & Swindle, 1983; Lazarus & Folkman, 1984; McCubbin & McCubbin, 1987). Resources are characteristics, traits or competencies of the various systems within the environment, such as the individual, family, or community (McCubbin & McCubbin, 1987). These resources may be tangible, such as money, or intangible, such as self-esteem. Heller and Swindle (1983) list both social resources (social connections) and personal resources (person characteristics) in their model.

Social connections. In the model of social support and the coping process, the environment provides social connections. Social connections are behaviors or interactions provided by others in one's environment. The environment includes ecological, community, family, and peer influences. It provides settings with opportunities for interaction with others. There are many social environments such as the workplace, school, community league, family home, etc. The family environment provides the opportunity to establish social connections with family members. The family network is an informal network, consisting of relationships formed through normative interpersonal association (Litwin & Auslander, 1990).

Heller and Swindle (1983) refer to Marsella and Snyder's (1981) network characteristics to describe social connections/networks. According to Marsella and Snyder (1981) the family network can be characterized by:

1) *Structure* which includes variables that describe and quantify the network such as size, density, and the individual's position within a network. This characteristic may include the number of family members in the caregiver's family network or the number of contacts the caregiver has with family members.

2) *Interaction* describes the relationships between network members such as reciprocity, symmetry, and single or multiple linkages between members. This characteristic may include whether the caregiver's relationships with other family members are reciprocal, providing an atmosphere of equality and mutual concern.

3) *Quality* describes the affective content of interactions such as level of friendliness, intimacy or affection based on an individual's perception. This characteristic includes the general atmosphere of the caregiver's family relationships, such as cohesive, nurturing, intimate, conflictual, or distant relationships.

4) *Function* includes variables that identify and describe the relationships in which an individual serves a function for another individuals such as the provision of information and feedback, comfort and cheer, material aid, advice, etc. This characteristic may include the kinds of help family members provide for the caregiver such as practical help (eg. household repairs) or emotional help (eg. listening to the caregiver talk about his or her feelings).

Heller and Swindle (1983) argue that these elements of social connections are not the same as support. The caregiver's family network may provide supportive interactions, but it may also provide negative interactions (Pagel, et al., 1987; Rook, 1984), particularly in stressful situations (Semple, 1992). Thus, Heller and Swindle (1983) emphasize that social connections or networks refer to interactions available in the environment that vary in terms of structure and function. Perceived support refers to the subjective impact of the interactions on the individual. This subjective appraisal falls under the concept of cognitive appraisal (see Figure 1). Heller and Swindle (1983) maintain that it is the individual's

perception or appraisal of his or her network as supportive that is important in the stress and coping process.

Person characteristics. In addition to social connections, Heller and Swindle's (1983) model incorporates person characteristics. In Figure 1, the genetic and constitutional predisposition and behaviors reinforced in early development influence an adult's person characteristics. Heller and Swindle (1983) describe person characteristics as "assets such as attractiveness, athletic skill, gregariousness, and relational skills, all of which can serve as 'entrance tickets' to many roles and relationships" (p. 96). These researchers go on to state that:

> The level of support enjoyed by the individual depends not only upon environmental structures and the actions of others, but also on the individual's abilities and predilections to link to others and elicit support from them. (p. 96)

Heller and Swindle (1983) use examples to illustrate how an individual will choose social networks according to the values or beliefs which he or she holds. This may be appropriate when discussing friendship networks but not necessarily when discussing family networks. Friendships are voluntary in nature, with bonds characterized by affection, consensus, and homogeneity (Chappell, 1992). Family ties, on the other hand, are non-voluntary, with bonds characterized by obligation, stability and length, and constrained by social and cultural norms (Gottlieb, 1983; Procidano & Heller, 1983). Although person characteristics may influence social connections, they may have less impact on family networks than on friendship networks due to the nature of these networks. For this reason, person characteristics, although part of the model, were not examined in the relationship between family network characteristics and perceived family support in the present study.

Perceived Social Support

Heller and Swindle (1983) distinguish between social networks and social support. Social networks are part of environmental resources; social support is part of cognitive appraisal. Some background to the concept of social support may help to clarify the placement of social support within the realm of cognitive appraisal.

There are two aspects of social support which can be derived from definitions found within the literature. First, social support refers to an interaction between an individual and a person or group within his or her environment. Hence the term "social" support. Social support has been defined as the existence or availability of people on whom an individual can rely; people who let the individual know that he/she is cared about, valued and loved (Sarason, Levine, Basham & Sarason, 1983). Kaplan, Cassel and Gore (1977) view social support as social interaction that assists in meeting the needs of people. Heller and Swindle (1983) suggest that social support is an appraisal of the interaction between an individual and another person or group in his or her environment.

Second, the definitions of social support state or imply that the interaction(s) serve to meet need(s) or goal(s) of the individual. Tolsdorf (1976) defined social support as "any action or behavior that functions to assist the focal person in meeting his personal goals or in dealing with the demands of any particular situation" (p. 407). When an interaction is deemed as adequate or appropriate to meet one's needs or goals, there must be some appraisal or evaluation involved in order to determine adequacy or appropriateness. Social support involves the subjective perception or belief of the individual that the interactions are beneficial. Cobb's (1976) definition addresses the subjective aspect of social support. He views social support as information leading an individual to believe that he is cared for and loved, esteemed and valued, and a member of a network of communication and mutual obligation.

Heller and Swindle (1983) have placed social support in the realm of cognitive appraisal because of the subjective evaluation aspect of the concept. Social support within the present study was also considered part of cognitive appraisal. This study focused on the caregiver's perception or appraisal of family support within a caregiving situation.

Reaction Patterns

Heller and Swindle's (1983) reaction patterns is a similar concept to coping (Lazarus & Folkman, 1984; McCubbin & McCubbin, 1987). The individual must

react or respond to the environmental demands. Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). They emphasize that coping is a process, not an outcome. A person in a specific situation manages the demands of the situation using various strategies or actions. These authors also highlight that coping is managing the situation, not mastering it. Not all sources of stress in the environment can be mastered. The term managing can include minimizing, avoiding, tolerating, and accepting the situation as well as attempting to master the environment. One reaction or management strategy may be support-seeking (Heller & Swindle, 1983). Whether an individual engages in support-seeking or not is determined by his or her appraisal of support adequacy. For example, a caregiver who appraises his or her support as less than adequate to meet the demands of the situation may seek new interactions with others to contribute to his or her perception of support.

Conceptual Relationship Addressing the Research Question

The Heller and Swindle (1983) model of social support and the coping process provides an understanding of how caregivers may function in the caregiving situation. To summarize, the caregiving environment places demands upon the caregiver, which may be stressful. The caregiver appraises the situation and the resources available in his or her environment to deal with the situation. The appraisal of his or her social connections (ie. family network) to provide the help or comfort needed by the caregiver may lead to a perception of adequate or inadequate family support. If the caregiver's social connections are deemed inadequate to meet the demands created by the environment, the caregiver may resort to support-seeking (Heller & Swindle, 1983).

The present study was built around a specific aspect of the caregiving situation; the caregiver's appraisal of family support. Hence, the conceptual relationship between social connections and cognitive appraisal was extracted from Heller and Swindle's (1983) model (see Figure 2). This relationship addresses the

question posed in this thesis: Do family network characteristics discriminate between caregivers who perceive family support to be adequate and those who perceive family support to be less than adequate?

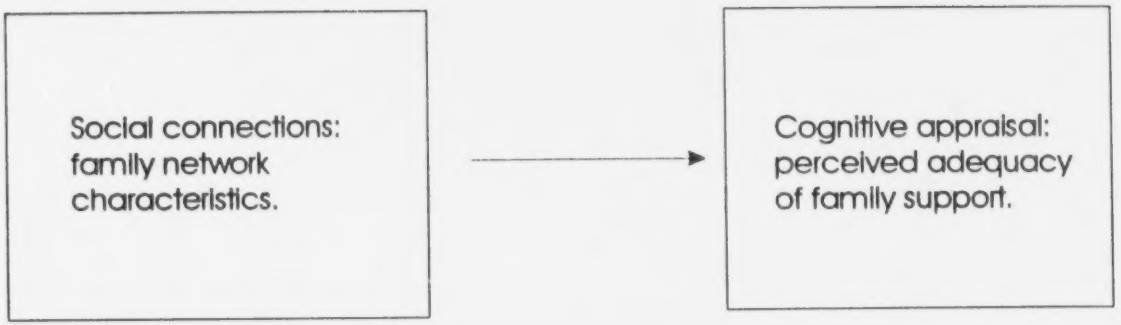


Figure 2. The Relationship Between Family Network Characteristics and Perceived Family Support.

# III. LITERATURE REVIEW

According to the model of social support and the coping process (Heller & Swindle, 1983) discussed in chapter two, there is assumed to be a link between family network characteristics and the caregiver's perception of family support. The four dimensions of network characteristics discussed in chapter two (Marsella & Snyder, 1981), helped to organize the choice of family network characteristics examined in the present study. *Structure* is the dimension which refers to morphological variables that describe and quantify the network. *Interaction* consists of variables that describe the relationships between the various network components. The dimension of *quality* describes the affective content of interactions based on an individual's perception. Finally, *function* includes variables that identify and describe the relationships in which an individual serves a function for another individual.

The following review of the literature identifies pertinent network characteristics that have been investigated in relation to perceived social support. These network characteristics, which can be applied to family networks, fall into the four dimensions mentioned above. For the dimension of structure, the social network size and family help specific to the problem were reviewed. For the dimension of interaction, the reciprocity of network relationships and the frequency of contact with network members was addressed. For the dimension of quality, general family functioning was discussed. Practical help received and emotional help received from family members, were considered under the dimension of function (see Figure 3). The aspect of time was also included as a family characteristic. Heller and Swindle (1983) emphasize that support is dynamic in nature, changing at various times within an individual's life. Family members' strengths and capabilities to help each other is influenced by their experiences and knowledge. Over time, the family members experience various situations which may affect the amount or type of help which they provide to each other. Thus, time since diagnosis was included in the list of family characteristics. Eight family network characteristics which may affect perceived support are discussed.

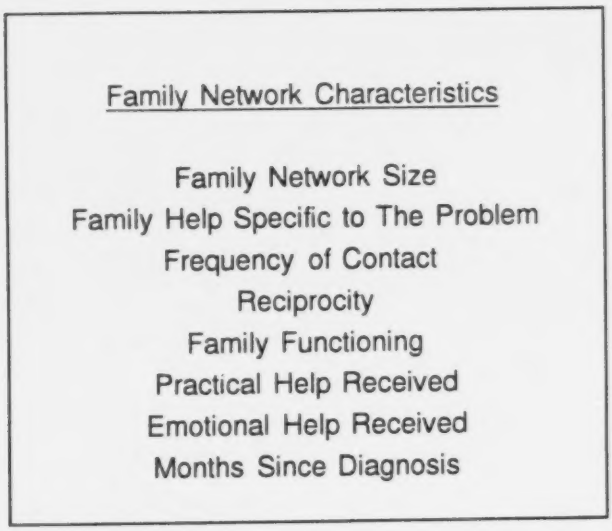


Figure 3. Variables Which May Influence the Caregiver's Perception of Family Support.

## Family Network Characteristics

### Network Size

Network size is considered a characteristic of network structure (Marsella & Snyder, 1981). In the social support and coping model, family network members are considered resources (Heller & Swindle, 1983) which may influence the individual's perception of support. Since social network members must exist for them to be a potential source of help, larger networks may be perceived as more supportive than smaller networks because there is the potential from help from more people.

Stokes (1983) examined the relationship between network size and perceived support. With a sample of 82 university students, he compared social network characteristics with the subjects' perceptions of the supportiveness of their

networks. Results indicated that subjects with very small networks felt less supported than subjects with larger networks. In contrast to this finding, Vaux and Athanassopulou (1987) assessed the relationship between network size and perceived support through telephone interviews of 138 community-residing adults. These authors found that total network size (including both friends and family) was not related to perceived support. Pagel and colleagues (1987) also found that network size was not significantly related to perceived support when examining the networks of caregivers of Alzheimer's patients. However, these researchers found that caregivers who were less satisfied with the support from their networks had a higher proportion of family members in their networks than caregivers who were satisfied with support from their networks.

The above studies provide contrasting evidence for a relationship between network size and perceived support. However, none of the above studies focused directly on the relationship between family network size and caregivers' perceptions of the adequacy of family support. First, Stokes' (1983) and Vaux and Athanassopulou's (1987) studies did not use caregivers in their samples. Caregivers are in a long-term, demanding situation which may require networks which differ from other situations. Second, none of the studies differentiated between family members and friends within the network. Friendships are voluntary in nature and are based on affection, consensus and homogeneity (Chappell, 1992). Family relationships, conversely, are non-voluntary and are based on obligation, stability, and length (Gottlieb, 1983; Procidano & Heller, 1983). The social and cultural norms dictating these relationships may differentially affect the perception of support from each of these groups.

In summary, research studies have not provided a clear picture of the relationship between family network size and perceived family support. According to the theoretical model, network size, as a characteristic of the social connections, should influence perceived support (Heller & Swindle, 1983). This study addressed this relationship by examining whether or not family network size influenced the caregiver's perception of the adequacy of family support.

Family Help Specific to the Problem

Family help specific to the problem refers to the number of family members who provide help specific to caregiving. This is considered an aspect of the dimension of structure because it quantifies the family network (Marsella & Snyder, 1981). Family help specific to caregiving is similar to network size in that the number of family members is counted. However, this network differs conceptually from the total family social network in that it is based on the number of family members who are involved in caregiving.

One of the reasons for examining the number of family members providing help specific to caregiving is that assessment of general interactions with one's network may not tap network responses specific to the event (Wethington & Kessler, 1986). Theories of stress, social support, and coping (Cohen & Willis, 1985) suggest that certain situations demand certain resources and responses. For example, a caregiver with the added duties of caregiving may not need the financial aid of a person experiencing bankruptcy. However, the caregiver may need someone to watch the ill relative while she runs an errand or sleeps. If the caregiver has more family members who provide help specific to caregiving, his or her perception of support may differ from a caregiver who has few or no family members providing this help because the needs created by the caregiving situation are being met.

In summary, no research evidence was found for a relationship between the number of family members providing help specific to caregiving and the caregiver's perception of family support. According to Heller & Swindle's (1983) model, the number of family members providing help specific to caregiving, as a family network characteristic, should influence perceived support. The present study investigated whether or not this relationship exists.

Frequency of Contact with Network Members

The frequency of contact with other family members is a characteristic of the dimension of interaction because it provides a description of the relationships between the caregiver and other family members (Marsella & Snyder, 1981). It

provides information on the amount of interaction. Research indicates that the frequency of contact between network members and the individual may influence perceived support. Fiore, Becker and Coppel (1983) examined the social networks (family and friends) of 44 caregivers with spouses diagnosed with Alzheimer's disease. Frequency of contact with network members was significantly correlated with ratings of perceived helpfulness or support. Kiecolt-Glaser, Dyer and Shuttleworth (1988) also examined social interactions and support with caregivers of relatives with Alzheimer's disease. Their results showed that greater frequency of contact with social network members was associated with greater perceptions helpfulness or support.

A study with university students showed similar results. Cutrona (1986) found that university students who reported higher levels of perceived social support had higher rates of interaction with others than university students who reported low levels of perceived support, particularly following a stressful event. Cutrona (1986) suggested that contacts with network members (both friends and family) contribute to people's evaluations of the adequacy of their social support.

In summary, the above studies suggest that frequency of contact with network members would influence the caregivers' perception of support. However, these studies do not specifically address the relationship between family networks and caregivers' perceptions of support. Cutrona's (1986) study did not use caregivers in the sample. All the studies did not differentiate between friends and family within the networks. According to the theoretical framework, interaction, as a characteristic of social connections, is expected to influence perceived support. The present study addressed whether or not this relationship exists.

Reciprocity

Reciprocity is a characteristic of the dimension of interaction because it describes the relationships between the caregiver and other family members (Marsella & Snyder, 1981). Reciprocity refers the degree to which a relationship involves equal "give and take" (Vaux & Athanassopulou, 1987). Reciprocity in social exchanges is very important to the maintenance of self-worth (Wetowski,

1981). Nonreciprocated social exchanges can threaten the recipient's status, power, and freedom and decrease the request for assistance by the recipient (Greenberg & Shapiro, 1971). Since the perception of social support stems from feelings of love, self-worth, acceptance, or feelings that one's needs are being met (Cobb, 1976; Sarason, et al., 1983), then reciprocity in social relationships should lead to a positive perception of support.

Studies with samples from the general population examined reciprocity and perceived support. Vaux and Athanassopulou (1987) addressed the relationship between reciprocity and perceived social support. Using telephone interviews with 138 community-residing adults, these authors collected data regarding social networks and perceived support. A positive correlation was found between reciprocity and perceived support. Stevens (1992) studied the family relationships of seniors ages 60-90. She found that reciprocity was significantly and positively correlated with life satisfaction, including satisfaction with support. McFarlane, Norman, Streiner and Roy (1984) reported that greater proportions of reciprocal relationships with an individual's social network was significantly related to a more positive perception of the network's helpfulness.

Results from the above studies would indicate that reciprocity influences perceived support. However, none of these studies specifically addressed caregivers' perceptions of family support. The above studies did not have samples of people in a long-term stressful situation such as caregiving. In addition, the studies discussed did not differentiate between friends and family members within the social networks. The present study investigated the relationship between reciprocity, as a family characteristic, and the caregiver's perception of family support.

Family Functioning

The term family functioning refers to the family social climate (Moos & Moos, 1986). This fits within the dimension of quality because it describes the affective content of interactions between the caregiver and other family members (Marsella & Snyder, 1981). A caregiver's evaluations about the adequacy of

support may be influenced by the overall quality of the relationships with other family members (Gottlieb, 1991). Moos and Moos (1986) view the family social relationships as indicative of family types (eg. support-oriented families). Some patterns of interaction are deemed more supportive than others. Moos and Moos report the following:

> In general, supportive family environments, characterized by high cohesion and expressiveness and low conflict, are associated with family member's better adjustment and greater ability to deal with stress, especially when coping with personal physical illness or a spouses' mental and behavioral problems. (p.30)

Matthews and Rosner (1988) suggest that family ties affect the participation styles of secondary family caregivers. A family has long-standing expectations of help, decision-making, and participation in life events that are in place before caregiving begins (Matthews & Rosner, 1988). These patterns of interactions may influence how family members help the caregiver and the caregiver's perception of family support. Gubrium (1988) demonstrates this with a qualitative analysis of caregivers of Alzheimer's relatives. He suggests that the family history of interacting affected the caregivers' perceptions of family support. For example, when the "black sheep" of the family was diagnosed with Alzheimer's disease, the caregiving spouse received very little help or comfort from the ill relative's family of origin. The history of being on the periphery of the "family circle" continued throughout the caregiving years and the caregiver felt unsupported by family members. Thus, it appears that a family history of interaction and helping behaviors (or lack thereof) circumscribes the help within the caregiving situation and influences the caregiver's perception of family support.

In summary, researchers have suggested that there are certain patterns of family interactions that are deemed as more supportive than others (Moos & Moos, 1986). During the caregiving situation, the general patterns of interaction, along with expectations and obligations, may determine how the family members are involved in caregiving duties (Matthews & Rosner, 1988). According to the

theoretical framework, quality, as a characteristic of the family network, should influence perceived support. Empirical and conceptual conclusions suggest that family functioning should influence the caregiver's perception of family support.

Practical Help Received

Marsella and Snyder's (1981) dimension of function includes what individuals and network members do for each other within their relationships. Practical help, which includes tangible forms of assistance, such as lending money, domestic help, providing transportation, etc., fits within the dimension of function because it describes what family members do for/with the caregiver.

The amount of practical help received from family members may influence the caregiver's perception of family support. Looking at the sibling relationships of caregivers of parents with Alzheimer's disease, Brody and colleagues (1989) found that distressed caregivers reported receiving little practical help. Scott, Roberto and Hutton (1986), also examining family support to primary caregivers, found that caregivers who perceived support as adequate received more practical help from family members than those who perceived support as less than adequate.

Within the general population, Cutrona (1986) found that practical help was not significantly correlated with university students' perception of support. Wethington and Kessler (1986), using a national sample of adults between ages 21-65, also reported that practical help received was not significantly correlated with the perception of support. These findings differ from those of the studies with caregiver samples.

Evidence for a link between practical help received and perceived support is contradicting within the literature. It seems that the studies which found a relationship between practical help received and perceived support used samples of people experiencing a stressful event (ie. caregivers). The other studies did not. Perhaps the amount of practical help received is particularly salient for those experiencing a stressful situation which demands this resource (Cohen & Willis, 1985). The practical help a caregiver receives from other family members may contribute to a perception of support because the caregiver is receiving resources

to meet the needs created by the situation (Lazarus & Folkman, 1984). The present study investigated the relationship between practical help received and the caregiver's perception of family support.

Emotional Help Received

Emotional help refers to intangible forms of assistance such as giving advice, verbal reassurance, listening, etc. This falls within the dimension of function because it describes what family members do for the caregiver (Marsella & Snyder, 1981). With a sample of caregivers, Brody and colleagues (1989) found that emotional help from siblings made caregivers feel supported. Cutrona (1986) reported that emotional help was associated with higher levels of perceived support in university students. In contrast to these findings, Wethington and Kessler (1986) found no significant relationship between emotional help received and perceived support for a national sample of adults.

In summary, there is evidence in the literature for both a positive relationship and no relationship between emotional help received and perceived support. The above studies do not directly address the relationship between emotional help received from family members and the caregiver's perception of support. Cutrona's (1986) study and Wethington and Kessler's (1986) study did not use samples of caregivers, or even people experiencing a specific event. In addition, these two studies did not distinguish between emotional help received from friends and emotional help received from family members. In the study by Brody and colleagues (1989) the emotional help received was assessed with a restricted sample of family members (ie. siblings only).

The needs created by the caregiving situation may not only be for practical help but may also be for emotional help. Emotional help may affirm or comfort the caregiver as he or she experiences the caregiving role. According to the theoretical framework, emotional help, as a family network characteristic, may influence the caregivers perception of the adequacy of family support. The present study addressed this relationship.

Months Since Diagnosis

Heller and Swindle (1983) emphasize that support is dynamic and changes in varying situations. Caring for a relative with Alzheimer's disease is also a dynamic situation. Alzheimer's disease involves a progressive deterioration of the ill relative's functioning and gradually requires more intense care (Robertson & Reisner, 1982). As the disease progresses and the demands of the caregiving situation change, the caregiver's perception of the adequacy of family support to meet his or her increasing needs may also change. The amount or types of help which the caregiver was receiving from family members may not have changed, but the demands of the situation have increased so that the help no longer meets the demands. Unless the family members adjust the help they provide, the caregiver may perceive his or her support to be less than adequate.

Gottlieb (1991) addresses the effects of caregiving over time on the help provided by family members from a slightly different angle. He suggests that the demands and strains of the situation wear and tear at the help that family members provide. Thus, one of the reasons that time since diagnosis may affect perceived support is that the family members are worn-out and can no longer provide the help that they could when the illness was first diagnosed. This is a characteristic of the family network.

In summary, time within the caregiving situation can have an effect on a caregiver's perception of family support, either because the level of help no longer meets the needs of the situation or because the family members are worn-out. According to Heller and Swindle (1983), family resources are not static, but change in various situations. In consideration of theoretical and empirical views, time since diagnosis is expected to influence the caregiver's perception of family support.

## Research Question

Eight family network characteristics which may influence perceived support were discussed in this literature review. Evidence was found for a link between many of the variables and perceived support (Brody, et al., 1989; Cutrona, 1986; Fiore, et al, 1983; Gubrium, 1988; Kiecolt-Glaser, et al., 1988; Scott, et al., 1986;

Stokes ,1983; Vaux & Athanassopulou, 1987). However, in the absence of consistent measures of perceived support with similar population samples, it is difficult to compare many of these studies. Thus, researchers do not have a clear idea of the family network characteristics which influence a caregiver's perception of family support. Based on the conceptual framework and the review of the literature, the following question was examined: Do family network characteristics discriminate between caregivers who view family support as adequate and those who view family support as less than adequate?

# IV. METHODOLOGY

## The Caring Project

This study was based on information collected in a longitudinal study entitled "The Caring Project" at the University of Alberta, funded through National Welfare Grants, Health and Welfare Canada. The Caring Project examined the dynamics of family caregiving to relatives with Alzheimer's Disease, particularly its impact on the primary caregivers' decision to institutionalize. The study was conducted by Dr. Sharon Warren, Faculty of Rehabilitation Medicine, Dr. Norah Keating, Department of Human Ecology, Dr. Michael Grace, Faculty of Medicine, Dr. Dana Wertenberger, Faculty of Nursing and Ms. Karen Kerr, Department of Human Ecology. The purpose of the Caring Project was to identify factors which predict the length of time that Alzheimer's patients are kept at home by their primary caregiver, focusing on aspects of extended family involvement.

## Sample

Participants consisted of primary caregivers of community-residing Alzheimer's patients from various cities and towns within the province of Alberta. Criteria for inclusion in the study included: 1) the ill relative must be diagnosed or confirmed with Alzheimer' disease by a physician; 2) the ill relative must be living in the community; 3) the primary caregiver and ill relative must reside in Alberta; 4) the primary caregiver must be a relative of the Alzheimer's patient. Participants who identified themselves as the primary caregiver were interviewed.

## Data Collection

Primary caregivers were recruited through hospitals, research programs, adult day support programs, the Alzheimer's Societies, newspaper announcements. Caregivers indicated interest by mailing in an interest form or by indicating interest to a professional at one of the recruitment centres. After interest was indicated on the part of the volunteer caregivers, these caregivers were contacted by The Caring Project Coordinator to request their cooperation and participation in the study.

Interviews were conducted by The Caring Project coordinator. The goal of the project was to interview the caregiver on a yearly basis until the patient was institutionalized or until three years had passed. The majority (69%) of caregivers were interviewed within two years of diagnosis. Only the person who identified himself or herself as the primary caregiver was interviewed. Interviews were conducted primarily in the caregiver's home, with other interviews taking place in public buildings, such as a hospital. Interviews were conducted using a questionnaire.

The questionnaire was compiled by the Caring Project team after identifying pertinent variables from the literature regarding predictors of institutionalization. The questionnaire requests information regarding demographics; family interaction, help, and functioning; perceptions of support and burden; the cognitive and physical abilities of the ill relative; utilization of coping strategies; and the use of formal services. Using the questionnaire, interviews lasted approximately two hours.

## The Present Study

The purpose of the present study was to examine if family network characteristics could discriminate between caregivers who view family support as adequate and those who view family support as less than adequate. It was the relationship between family network characteristics and the caregiver's perception of support adequacy that was the focus of this study (see Figure 2).

The choice of family network characteristics was derived from Marsella and Snyder's (1981) four dimensions of social networks described in the literature review. The Caring Project protocol did not include data for all of the characteristics suggested by Marsella and Snyder (1981). However, at least one family network characteristic within each dimension was examined. In total, eight family network characteristics were included in the study: family network size, family help specific to caregiving, frequency of contact, reciprocity, family functioning, practical help received, emotional help received and the number of months since diagnosis.

This study used cross-sectional data obtained in the first set of interviews collected in the Caring Project.

In addition to the eight family network characteristics, three control variables were incorporated in the analysis. These variables included: age, gender, and years of education. These demographic variables were chosen because there is evidence in the literature linking them to perceived support.

The variable of age has been found to correlate with perceived support. With a national sample of 1269 adults, Wethington and Kessler (1986) found that age was positively correlated with perceived support from one's network. McFarlane, Normal, Streiner and Roy (1983, 1984) found that older adults perceived their social networks as more helpful than younger adults. The younger age of the caregiver has also been associated with the preference to institutionalize the ill relative (Colerick & George, 1986; Gilhooly, 1986). Authors have suggested that it is dissatisfaction with network help leading to increased burden which influences the link between age and preference for institutionalization (Colerick & George, 1986; Gilhooly, 1984). Rosenthal (1987) found the older adults were less likely to identify family members who provide emotional help. She suggested that the elderly are less integrated into the extended family than younger family members. This decrease in the ability to identify family helpers may also influence an older caregiver's perception of family support.

The variable of gender has also been associated with perceived support within the literature. Studies with samples from the general population provided evidence that women had more positive perceptions of family network and total network support (Antonnucci & Akiyama, 1991; McFarlane, et al., 1983, 1984; Stolar, MacEntee & Hill, 1993; Wethington & Kessler, 1986). Colerick and George (1986) found that female caregivers were more likely to institutionalize an ill relative than male caregivers. They suggested that the decision to institutionalize was related to feelings of social isolation and lack of support.

Results from research studies indicate that years of education may influence perceived support. Kosberg, Cairl and Keller (1990) found that caregivers with

more years of education perceived less social interaction and help from their social networks. Studies from the general population show that years of education is positively correlated with perceived support (Wethington & Kessler, 1986) and with comfort and relief from one's network (McFarlane, et al, 1983). Thus, evidence linking age, gender, and years of education to perceived support suggest that these variables may contribute to caregiver's perceptions of family support. These variables were not considered to be family network variables and were, therefore, used as control variables.

## Operational Definitions of Variables[1]

### Dependent Variable

1. Adequacy of support. The perceived adequacy of help which caregivers receive from family members was assessed on a three-point item created by Scott and colleagues (1986). The three categories included "more than adequate", "adequate enough", and "less than adequate." After an open-ended interview, two raters coded the caregivers into one of the three categories based on comments made by the caregivers during the interviews. Caregivers were not asked to rate the adequacy of family support directly. A rating of more than enough support indicated that the family more than met the caregiver's expectations for support, including a perception that other family members were willing to help and share problems. A rating of enough support indicated that the caregiver made no mention about needing more support or about lack of support. A rating of less than enough support indicated that the caregiver was not receiving as much support from the family as he or she wanted or that the family members were adding to the caregiver's problems. Interrater reliability for this item was 86% (Scott, et al., 1986).

For the present study, caregivers were asked to rate the adequacy of family support directly. This question was asked of the caregivers after a number of family network scales and protocols had already been completed. In this manner,

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[1]See Appendix A for questionnaire items.

the caregivers had already been thinking about the family members who provide help or comfort, as well as what they do in relation to the situation. The caregivers were asked to rate the support which they get from other family members as either more than adequate, adequate enough, or less than adequate to their needs. For the analysis in the present study, the caregivers were placed into two groups based on their responses. One group indicated a more positive view of support, combining those caregivers who rated support as adequate enough or more than adequate. The other group, indicating a more negative view of support, included caregivers who rated support as less than adequate. All of the family network characteristics were examined based on these two groups.

Independent Variables

1. Family network size. A family tree was used to collect information on the size of the caregiver's family network. The family tree was designed by the Caring Project Team. For caregivers who were spouses of the ill relative, information was collected regarding siblings of the caregiver and ill relative, children and grandchildren. For caregivers who were children, grandchildren, or nieces of the ill relative, information was collected regarding parents, maternal aunts and uncles, paternal aunts and uncles, children and grandchildren. The family tree provided information as to the existence of both horizontal family branches (siblings) and vertical family branches (children, grandchildren, parents, aunts/uncles). The tree was not comprehensive in that data were not obtained regarding in-laws (eg. sister-in-law) or nieces/nephews. In addition, spouse caregivers were not asked for information regarding their parents, aunts or uncles because the advanced ages of spouse caregivers decreased the likelihood of their existence.

For the purposes of this study, the number of family members mentioned in the family tree was summed to determine the size of the caregiver's family network.

2. Number of family members providing help specific to caregiving. This item, patterned after the Social Relationship Scale (McFarlane, Neale, Norman, Roy & Streiner, 1981), was developed by The Caring Project team. Caregivers

were asked to list the family members who provide help specific to caregiving and to indicate the helpfulness of their behaviors on a 7-point scale. For the present study, the number of family members listed by the caregiver as people who help with caregiving was summed.

3. Frequency of contact with family members. This section of the questionnaire was developed by The Caring Project team. Caregivers were asked to list the family members with whom they had contact with in the past week and the number of contacts with each person. For the present study, the total number of contacts (regardless of number of family members) within the past week was calculated. This list did not include family members who lived with the caregiver because these interactions are of a more continuous nature and are difficult to reliably count. Interactions with the ill relative were also excluded because, for the purposes of this study, the ill relative was considered outside of the family support network.

4. Reciprocity. The measurement of reciprocity was derived from the Social Relationship Scale (McFarlane, et al., 1981). On this measure, the caregivers named family members with whom they discuss six categories of life events (work, money and finances, home and family, personal health, personal and social things, society in general) and the helpfulness of the discussions. In addition, the caregiver indicated whether or not (ie. yes or no) the family member named would reciprocate the discussion (McFarlane, et al., 1981). For example, if a caregiver indicated that she discusses home and family with her sister, she would also indicate whether her sister would approach her for a discussion on home and family. From tests conducted with married couples and college/university students, McFarlane and colleagues (1981) determined that the Social Relationship Scale: 1) had reasonable reliability over time; 2) did not elicit socially desirable responses; 3) contained content validity; 4) had reasonable criterion validity. No specific information was given as to the reliability and validity of the reciprocity section of the scale.

Reciprocity, for the purposes of the present study, was calculated as recommended by the authors of the scale (McFarlane, et al., 1981). The number of family members scored as reciprocal (indicated by a score of "yes") was divided by the total number of family members listed in all of the six categories of the scale. A percentage of reciprocal relationships was calculated.

5. Practical help received from family members. Caregivers indicated whether they had received certain types of practical help from family members (yes or no) from a list of instrumental behaviors. The receipt of instrumental help (ie. number of helpful behaviors) was developed by Scott and colleagues (1986) to assess the support provided to the caregiver from other family members. They defined instrumental assistance as "concrete" forms of help (eg. financial help, physical care of the patient, providing information, etc.). No reliability or validity data were collected for this protocol. For use within the Caring Project, the Caring Project Team altered or deleted some of the items and others were added to the list. For the purposes of the present study, the number of "yes" responses was summed to obtain a practical help received score. The possible scores for this protocol ranged between 0 and 13.

6. Emotional help received from family members. Caregivers indicated whether they had received certain types of emotional help from their family members (yes or no) from a list of non-tangible behaviors (eg. giving advice, listening to you talk about your private feeling, joking or using humor to try to cheer you up, etc.). The list of items indicating emotional help was developed by the Caring Project team. For the purposes of the present study, the number of "yes" responses was summed to obtain an emotional help received score. The possible scores for this protocol ranged from 0 to 13.

7. Family Functioning. The Family Relationship Index (FRI) (Holahan & Moos, 1983; Holahan & Moos, 1986), which was derived from the Family Environment Scale (Holahan & Moos, 1981), assesses the quality of social relationships in the family environment. The FRI consists of three subscales: *Cohesion* - the degree to which family members are helpful and supportive of each other; *Expres-*

*siveness* - the extent to which family members are encouraged to act openly and to express their feelings directly; and *Conflict* - the extent to which the open expression of anger and aggression and generally conflictual interaction are characteristic of the family. Each of the subscales has nine statements about family functioning which are rated dichotomously (i.e. true or false) by the care-giver. The responses can be scored with a key and translated into standard scores ranging from 1 to 81.

The researchers reported that the FRI has high internal consistency (Cronbach's alpha = .89), with a median intercorrelation among the three subscales of .43. Support for the construct validity of the Family Environment Scale has been established by over 50 studies that have used the scale in a variety of ways (Moos & Moos, 1986). The researchers suggested that supportive families score high on cohesion and expressiveness and low on conflict.

For the present study, a composite score was obtained by using the following equation (Moos, personal communication):

cohesion sum + expressiveness sum + 9 - conflict sum = total FRI

Each subscale had nine items. The conflict sum was reverse scored (subtracted from nine). Possible scores ranged from 0 to 24. A higher score indicated a more supportive family environment while a lower score indicated a less supportive environment.

8. Months since diagnosis. This item required the date that the ill relative was diagnosed or confirmed as having Alzheimer's disease by a physician. The number of months was calculated as the time difference between the date of diagnosis and the date of the first interview in months.

Control Variables

1. Age of caregiver. The age of the caregiver was indicated in years.

2. Gender of the caregiver. The gender of the caregiver was indicated as male or female. For the purposes of the study, this categorical variable was scored as a dummy variable (male=0; female=1).

3. Years of education. The caregiver's years of education was determined by the total number of years spent in elementary school, secondary school, and post-secondary education.

## Data Analysis

Discriminant analysis, which predicts group membership from a set of predictors, was the statistical analysis used in the present study. Discriminant analysis uses mathematical techniques to determine the way of computing scores that results in the best separation among the groups, that is the most accurate prediction of what group each case is in (Norusis, 1988). Discriminant analysis was used to determine how well a set of family network characteristics and a time variable discriminate between caregivers who feel supported by their families and those who do not.

One of the major questions in discriminant analysis is whether predictors can be combined to predict group membership reliably (Tabachnick & Fidell, 1989). In fact, discriminant analysis includes a process called classification, which compares the actual and predicted group membership of each subject to test how well group membership can be predicted based on the predictors or independent variables in the equation. Since there were two groups in the present study, there was only one way to combine the independent variables in order to differentiate between the groups. Discriminant analysis is a robust test in that no special problems are created by unequal sample sizes or violations of normality (Tabachnick & Fidell, 1989).

Family social network size, frequency of contact with family members, practical help received from family members, emotional help received from family members, the number of family members providing support specific to caregiving, family functioning, and the number of months since diagnosis were the independent variables hypothesized to discriminate between the two groups of caregivers. Caregiver age, gender and years of education were included as control variables. Based on the number of variables in the equation, a minimum sample size of 79 caregivers was required. (See Appendix B for sample size calculation.)

# V. RESULTS

Discriminant analysis was used to determine how well certain family network characteristics could discriminate between caregivers who perceived family support to be adequate and those who perceived family support to be less than adequate. This chapter begins with an overview of the sample characteristics. This is followed by the results of the discriminant analysis. The limitations of this study conclude this chapter.

## Sample Characteristics

The sample consisted of 91 primary caregivers of community-residing Alzheimer's patients. Primary caregivers included 46 spouses (33 wives, 13 husbands), 36 adult children (33 daughters, 3 sons), 6 daughters-in-law, 1 niece, and 2 granddaughters.

The caregivers' ages ranged from 31 to 84 years with a mean of 57 years. The ill relatives' ages ranged from 57 to 89 years with a mean of 75 years. The majority of caregivers were female (82%). The majority of caregivers lived with the ill relative (72.5%) and were not employed (58.2%). The average number of years of education was 13 with a range of 6 to 23 years. The majority of caregivers (88%) had some or all high school education. Caregivers generally described themselves as being in good (58%) or excellent health (26%).

The above sample was compared to samples of other studies of a similar nature. A review of studies with samples of caregivers of Alzheimer's or dementia patients showed that: the percentage of females ranged from 55 (Gilhooly, 1986) to 96 (Robertson & Reisner, 1982); the average age of the caregivers ranged from 57 years (Gilhooly, 1986) to 67 years (Mohide, Pringle, Streiner, et al., 1990); the percentage of spouses ranged from 42 (Robertson & Reisner, 1982) to 87 (Scott, et al., 1986); the percentage of adult children ranged from 34.4 (Harper & Lund, 1990) to 47.8 (Cohen & Eisendorfer, 1988); the caregivers who were employed included 28% of one sample (Colerick & George, 1986); the majority of caregivers have some or all high school education (Chenoweth & Spencer, 1986; Colerick & George, 1986; Mohide, et al., 1990; Scott, et al., 1986); the majority of caregivers

lived with the ill relative (Harper & Lund, 1990; Kinney & Stephens, 1989; Robertson & Reisner, 1982); and 65% of caregivers in one sample rated their health as good or excellent (Robertson & Reisner, 1982).

The present sample is similar to samples found in the literature with regard to: the percentage of females, educational attainment, and whether or not the caregiver lives with the ill relative. The average age of the caregivers and the percentage of spouses in the sample were at the lower end of the range found in other studies of this nature. More caregivers were employed and more caregivers rated their health as good/excellent in the present sample than in other studies with caregivers.

## Discriminant Analysis

Descriptive information regarding the independent, dependent and control variables is shown in Tables 1 and 2. All of the independent and control variables were continuous except for gender (gender was transposed into a dummy variable with male=0 and female=1). The dependent variable was categorical.

A univariate *F*-ratio analysis was performed using eight family network variables and three control variables to determine which variables to include as predictors in the discriminant analysis. Analysis was performed on the dependent variable of perceived adequacy of family support. Caregivers were placed into two groups. Group 1 consisted of those caregivers who perceived family support to be adequate or more than adequate. Group 2 included those caregivers who perceived family support to be less than adequate. Of the original 91 subjects, one was dropped from the analysis due to missing data. This left 90 subjects in the analysis.

Univariate F-ratio analysis showed that five of the eight predictor variables and one control variable significantly differentiated the groups (see Table 1). Therefore, six variables were entered into the discriminant analysis, omitting family network size, reciprocity, family functioning, gender and years of education. In order to control for age, a stepwise discriminant analysis was used. Age was entered first to control for its influence in the discrimination between the two groups

| VARIABLES | MEAN | ST.DEV. | MINIMUM/ MAXIMUM | UNIVARIATE $F(1, 88)$ |
|---|---|---|---|---|
| Family Network Size (# family members) | 4.25 | 2.4 | 0/10 | 2.58 |
| Number of Family Members Providing Help Specific to the Problem | 4.7 | 2.4 | 1/12 | 4.92* |
| Frequency of Contact with Family Members (# contacts) | 8.7 | 8.2 | 0/42 | 5.47* |
| Reciprocity (proportion of contacts) | 87.4 | 22.7 | 0/100 | 1.03 |
| Practical Help Received (# types) | 6.0 | 2.5 | 0/11 | 4.28* |
| Emotional Help Received (# types) | 8.8 | 2.8 | 0/12 | 4.10* |
| Family Functioning (total raw score) | 19.8 | 4.2 | 6/26 | 2.00 |
| Months Since Diagnosis (# months) | 20.4 | 23.9 | 1/118 | 4.35* |
| Age of caregiver (# years) | 56.7 | 14.4 | 31/84 | 3.97* |
| Gender of caregiver (female=1) | .8 | .4 | 0/1 | 0.29 |
| Years of Education (# years) | 13.3 | 3.1 | 6/23 | 0.17 |

**TABLE 1. Means, Standard Deviations, Ranges and Univariate Results of the Independent and Control Variables.**

*Significant at $p < .05$

**TABLE 2. Frequencies of the Dependent Variable.**

| VARIABLE | FREQUENCY | PERCENT |
|---|---|---|
| Adequacy of Help[1] | | |
| Adequate | 67 | 74.4 |
| Less than Adequate | 23 | 25.6 |

[1] Missing cases = 1

of caregivers. The five family network variables were entered next in accordance with the Wilks stepwise procedure which enters variables based on the value of Wilks Lamda. One discriminant function was calculated, with a $x^2$ = 21.98, p =.0005. The frequency of contact variable was excluded from the function because of shared variance with age, practical help received and the number of family members providing help specific to caregiving. The discriminant function, which consisted of four family characteristics and one control variable, accounted for 23% of the variance between the groups (Wilks' Lamda = .77). The structure matrix of correlations between the independent variables and the discriminant function was used for interpretation of the discriminant function (Munro, Visintainer & Page, 1986). As seen in Table 3, the structure matrix shows that the best predictors for distinguishing between caregivers who perceive family support as adequate and those who perceive family support as less than adequate are, in descending order: number of family members providing help specific to caregiving; months since diagnosis; practical help received; emotional help received: and age of caregiver. The above variables made joint contribution to distinguishing between caregivers who perceive family support to be adequate and those who perceive family support to be less than adequate.

In summary, caregivers who perceive family support to be adequate have: 1) more family members providing help specific to caregiving; 2) less time elapsed since the ill relative was diagnosed; 3) more practical help; and 4) more emotional help from their family members as compared to caregivers who perceive family support to be less than adequate. Caregivers who perceive family support to be adequate are also older than those who perceive family support to be less than adequate.

The classification results for the 90 subjects entered into the analysis indicated that 64 of 90 (65.6%) cases were correctly classified. Fifty percent or 45 of 90 cases would be correctly classified by chance alone. The classification rate

**TABLE 3. Correlations Between the Independent and Control Variables and the Discriminant Function.**

| INDEPENDENT VARIABLE | CORRELATION[1] | AMOUNT OF TOTAL VARIANCE[2] |
|---|---|---|
| Number of Family Members Providing Help Specific to Caregiving | .50 | 25% |
| Months Since Diagnosis | -.41 | 17% |
| Practical Help Received | .41 | 17% |
| Emotional Help Received | .40 | 16% |
| Age of caregiver | .39 | 15% |

[1]Correlation coefficients of .30 or greater are considered meaningful (Munro, et al., 1986).

[2]Portion of the 23% variance accounted for by the discriminant function.

for the caregivers who perceived family support to be adequate was slightly less (64.2%) than the classification rate for caregivers who perceived family support to be less than adequate (69.6%).

## Limitations

As with most research studies, there are limitations to the results found in the present study. The first limitation is generalizability. The results of this study will be most applicable to caregivers of non-institutionalized relatives with Alzheimer's disease. The experiences and family support for caregivers of institutionalized Alzheimer's relatives may be quite different due to the variations in the situation.

A second limitation is the sampling procedure. The present study used a non-random, volunteer sample. Non-random selection does not insure that all subject characteristics that correlate with the dependent variable are distributed equally between the sample and members of the population who did not volunteer, and between the two sample groups of caregivers (Smith & Glass, 1987). Although control variables help to reduce this problem, non-random sample selection is a limitation.

Finally, secondary analysis is a limitation of this study. The original study, from which secondary data were gathered, included operationalized constructs based on the theory and research question(s) of the original researchers. A secondary analysis, which often has a different focus from the original study, is limited by the measurements used and the type of data collected. Consequently, while the measures available were adequate for the purposes of this study, more detailed information would have enhanced the breadth of the measures. For example, the dependent variable (perceived adequacy of family support) was a global measure in the original study. It may have been useful to have gathered more specific information as to the perception of adequacy for particular kinds of family help or interactions.

# VI. DISCUSSION

The purpose of this study was to examine if family network characteristics influence the caregiver's perception of the adequacy of family support. Results of the discriminant analysis suggested that five of the eight variables identified as possible predictors of support did contribute to the caregiver's perception of adequate versus inadequate family support. Four of these variables were part of the discriminant function predicting group membership: number of family members providing help specific to caregiving, months since diagnosis, practical help received, and emotional help received. The control variable of age was also part of the discriminant function.

This chapter begins with a discussion of the findings reported in the previous chapter. Each family network characteristic and each control variable will be dealt with separately. Implications of the findings in terms of health and welfare provisions and future research will conclude the discussion.

## Family Help Specific to Caregiving

The number of family members who provide help specific to caregiving significantly contributed to the discrimination between caregivers who perceived family support to be adequate and those who perceived family support to be less than adequate. Specifically, more family members providing help lead to a perception of family support. Within a stress and coping framework, the situation can create specific environmental demands in addition to the everyday events and hassles which require a caregiver's attention (Heller & Swindle, 1983; Lazarus & Folkman, 1984). Larger numbers of family members attending to the new demands may be perceived as supportive by the caregiver because needs are being met. Theoretically, one aspect of perceived support is that an individual feels that his or her needs are being met (Kaplan, et al., 1977; Sarason , et al., 1983).

The number of family members providing help specific to caregiving focused on family members who discuss the specifics of caregiving situation which the caregiver is experiencing. This is a count of family members who are doing something for the caregiver. Perhaps the perception of support stems from the

ability to discuss the demanding situation with a variety of others. The caregiver may obtain a variety of assistance or advice from larger numbers of family members who are willing to discuss the provision of care to the ill relative. More family members may provide more resources to help the caregiver meet the demands of the caregiving situation. This in turn, may lead to a perception of adequate family support. It seems that the mere existence of family members (number alone) is not as crucial to a perception of adequate support as is the involvement of other family members in caregiving (number providing help). The key appears to be how many family members are doing something in relation to caregiving. This study showed us that the number of family members providing help specific to caregiving influences the caregiver's perception of family support. It may be beneficial to further examine this relationship to understand the how or why of this connection.

Months Since Diagnosis

As an aspect of the family network characteristics, months since diagnosis was a measure of possible differences in family help or interaction based on length of time since the official diagnosis of Alzheimer's disease. Months since diagnosis made the second strongest contribution to the discriminate function in predicting caregivers' group membership. Heller and Swindle (1983) suggested that support is dynamic, not static over time. It is possible that support may be perceived differently when a caregiver is adjusting to the news of the diagnosis and the new role as caregiver than when he or she has been caregiving for a while. These results indicate that caregivers feel more supported when fewer months have elapsed since diagnosis.

It should be acknowledged that caregiving does not necessarily begin at diagnosis. Often, a caregiver has assumed the responsibility and duties of caregiving before Alzheimer's disease has been diagnosed. By the time the disease is officially diagnosed, the symptoms of Alzheimer's disease may be quite pronounced. However, date of diagnosis was chosen as the point from which to assess differences in family help or interaction because of the general accuracy

of the date compared to when the caregiver first noticed symptoms or actually began caregiving and because of the impact which the official diagnosis may have on family help or interaction. For example, a family member who does not think there is a problem may interact differently with the caregiver or ill relative before diagnosis than after, perhaps based on the authority of the diagnosing physician.

Two possible explanations for the finding that months since diagnosis influences perceived family support will be addressed. First, family members may be willing to provide a certain amount of help and comfort to the caregiver. This assistance may be adequate in the early stages of caregiving, when the demands created by effects of the disease are not yet fully realized. Over time, the situation changes. The progressive deterioration associated with Alzheimer's disease decreases the ill relative's functioning and increases the demands of care. The amount of help which the family members provide may no longer be adequate to meet the increased demands of the situation. Unless the family members reassess and change their contribution to the situation, the caregiver may perceive family support as no longer adequate to meet the demands of the situation.

A second possible explanation for this finding may be that family members become fatigued. Gottlieb (1991) suggests that the demands and strains of the situation exhaust the help which family members can or are willing to provide. As time goes by, family members are no longer able or willing to maintain the amount of help or comfort they had been providing previously. This change in help may lead to the caregiver's appraisal of less than adequate support.

### Practical Help Received

The amount of practical help received from family members contributed to the discrimination between the two groups of caregivers. Caregivers who received more help felt more supported. Theoretically, the amount and variety of practical help received from family members in response to a stressful situation can be deemed a resource (Cohen & Willis, 1985; Lazarus & Folkman, 1984). The more resources which the caregiver has to meet the demands of the caregiving situation, the more supported he or she may feel.

The amount of practical help received was assessed by asking the caregivers if they received certain kinds of help from family members (ie. domestic help, transportation, etc.). The amount of help received was limited to the choices available and by a response of yes or no instead of an indication of the number of times the help was received. For example, a distinction could not be made between caregivers who received domestic help once per week or five times per week. However, even with the limitations, the amount of practical help received influenced perceived support. This finding is in accordance with other studies of caregiving within the literature (Brody, et al., 1989; Scott, et al., 1986).

Emotional Help Received

The amount of emotional help received significantly contributed to the discrimination between the two groups of caregivers. Specifically, caregivers who received more emotional help felt that family support was adequate to meet their needs. Watching the effects of Alzheimer's disease on a loved one can be an emotional experience. The caregiving situation may create emotional needs of comfort, reassurance, etc. for the caregiver. Family members who provide emotional help are providing resources to meet the demands created by the situation (Lazarus & Folkman, 1984). Family support may be perceived as adequate when more emotional needs are being met. This point arises from the view that feelings of being love, valued, cared for and being part of a community lead to perceptions of support (Cobb, 1977; Sarason, et al., 1983).

The limitations of this variable are similar to those of practical help received. The caregivers were asked to indicate whether or not they received a particular kind of emotional help from a predetermined list. The responses were confined to the choices available and to an answer of yes or no. However, even with the limitations, the amount of emotional help received from family members influenced the caregiver's perception of family support. It may be beneficial to further explore the relationship between practical and emotional help received and perceived support by giving the caregiver more freedom to express how this help meets his or her needs.

Frequency of Contact with Family Members

The frequency of contact which the caregiver has with family members made a strong contribution to the distinction between caregivers who perceived family support to be adequate and those who perceived family support to be less than adequate. However, this variable was not part of the discriminant function predicting group membership because of its shared variance with other variables in the equation. Even though frequency of contact with family members was removed from the analysis, it may still an important variable in differentiating between caregivers who perceive family support to be adequate and those who perceive family support to be less than adequate.

Results indicated that caregivers who had more contact with their family members felt more supported. It is possible that caregivers with greater amounts of contact with families members feel valued, cared for, and loved. These feelings may lead to a perception of family support (Cobb, 1976). Perhaps caregivers who receive little or no contact from family members feel neglected and unimportant, leading to a perception of less than adequate support. These explanations stem from an assumption that contacts with family members are positive. It has been suggested in the literature that amount of contact with family members can include both positive and negative encounters (Pagel, et al., 1987; Rook, 1984). If negative interactions occur, then the frequency of contact with family members may not be perceived as supportive. Some researchers suggest that content of the interaction is more involved in the perception of support than the number of interactions (Pagel, et al., 1987; Rook, 1984). However, results of the present study suggest that the amount of contact with family members is related to perceived support.

In the present study, frequency of contact was assessed by asking the caregivers to list the family members they had contact with during the past week and to indicate the number of contacts. The quality of the interaction was not addressed. It is possible that caregivers only listed positive interactions. It is also possible that family members who provide negative encounters tend not to make many contacts with the caregiver, so that the number of negative interactions is

considerably less than the positive interactions within one week. One aspect of the frequency of interactions not considered, but that may be important, is whether the caregiver initiated the contact or whether other family members initiated the contact. Interactions initiated by others may lead to a perception of support because contact is offered to the caregiver rather than the caregiver requesting interaction. Although the present study indicated that frequency of contact influences perceived family support, it may be beneficial to know what aspects of the interactions (eg. who initiated the contact) may be important.

Frequency of contact was not included in the discriminant function because it shared variance with caregiver age, the number of family members providing help specific to caregiving, and practical help received. It makes sense that frequency of contact would moderately correlate with the number of family members providing help specific to caregiving and the amount of practical help received. Both of the latter variables require contact or interaction. Thus, more of each of the latter variables would be associated with more contact between the caregiver and other family members.

Two possible reason for the moderate correlation between frequency of contact and caregiver age will be addressed. First, a measurement issue will be discussed. Frequency of contact with family members did not include contact with family members who lived with the caregiver. It is possible that elderly caregivers, whose children live in separate dwellings, may have more contacts with family members outside the home than younger caregivers whose children may still be living in the same household because most of the younger caregivers contacts would be with live-in family members who were not counted in the measurement. Second, it is possible that increased age (along with possible health or mobility deterioration) promotes concern by adult children for the well-being of elderly caregivers which may not be a concern for family members of younger caregivers. Connidis (1989) emphasizes that adult children tend to have regular contact with their elderly parents. Concern for well-being may spur more regular contact from family members for older caregivers than for younger caregivers.

In summary, frequency of contact with family members made a significant independent contribution to the distinction between the two groups of caregivers, although it was removed from the discriminant function. This variable should not be discounted in research or practice when examining caregivers' perceptions of family support.

Family Network Size

This variable was not part of the discriminant analysis because it was not found to significantly differentiate between the two groups of caregivers in a univariate analysis. The size of the family network was determined by the number of family members listed by the caregiver as part of his or her family tree.

While it may be true that larger networks have a greater potential for providing support they may not necessarily do so. Clearly, it is not size alone that influences support, but rather the size of the helping network that counts. In the present study, the size of the family network was moderately correlated with the number of family members providing help specific to caregiving, practical help received, emotional help received and the frequency of contact with family members. It appears that greater numbers of family members may provide greater numbers of helping behaviors. However, they may not do so every time. This would appear to be the case, since family network size did not significantly contribute to the discrimination between the two groups of caregivers, while the other variables did. Large family networks providing help may be deemed more supportive than large family networks who do not provide help. This may be the difference between who is and who should be providing help.

A family may be viewed as supportive by the caregiver if the people who exist and should be providing support actually are providing support (Keating, et al., 1993). The "shoulds" are based on social norms which dictate a hierarchy of family obligations (Qureshi, 1990). The family members who are expected to participate in caregiving follow this general order: spouse, daughter, daughter-in-law, son, other relative (Qureshi, 1990). The influence that family size has on the perception of support may be based on the actions of the obligated family

members. This information was not available in the data base. It would be interesting to examine support based on perceptions of obligation.

Reciprocity

The variable of reciprocity was not included in the discriminant analysis because it did not significantly discriminate between the two groups of caregivers at the univariate level. Reciprocity was calculated as the proportion of family members who reciprocate general social interactions with the caregiver. Essentially, the percentage of reciprocal relationships was obtained. One possible reason for the lack of variance of this variable may have been the way it was calculated. A percentage makes it difficult to distinguish whether caregivers had no family members who existed to reciprocate, had very few family members who reciprocated, had many family members who did not reciprocate, or had many family members of whom only some reciprocated. One reciprocal relationship may be perceived differently from ten reciprocal relationships (Vaux & Athanassopulou, 1987). The calculation did not permit distinctions between the number of reciprocal relationships.

Reciprocity within the family is often assumed and may not always be immediate (Stolar, MacEntee & Hill, 1993). For example, a caregiver may assume that her sister would approach her for discussions regarding finances and money even though she has not actually done so. One of the limitations of the way in which reciprocity data was obtained in this study was that the caregiver was asked "Would this person come to you to discuss _____ ?" This is based on the expectation of reciprocity rather than the act of reciprocity. It is possible that caregivers listed family members in their social network with whom reciprocation is expected. Family members who would not be expected to reciprocate may have been excluded. This may account for the lack of variance between the two groups of caregivers. Closer examination of the variable of reciprocity is needed to clarify the relationships between reciprocity and perceived support.

## Family Functioning

The variable of family functioning was not included in the discriminant analysis because it did not significantly differentiate between the two groups of caregivers in a univariate analysis. This variable was originally included in the list of family network characteristics to examine how the quality of family interactions may contribute to the perception of support. This variable included the assessment of the cohesiveness, expressiveness, and conflict of general family interactions.

One possible reason why family functioning did not contribute to perceived family support may be the way that the questions were asked. The questions seemed to imply that the family resided together in one household (eg. "We say anything we want to around home." or "We rarely volunteer when something has to be done at home."). These questions may not be appropriate for an elderly spouse caregiver whose children have homes of their own. This may affect how the questions were answered. For example, the caregiver may be answering retrospectively based on when his or her children were still living at home. Another point is that the caregivers may have been thinking of certain family members when answering the questions. For example, some of the caregivers commented that they were answering the questions based on interaction with their spouse and children. Others indicated that they were considering their siblings and parents. It is possible that caregivers were basing their answers on the family members who they viewed as supportive. This may have contributed to the lack of variance between the two groups of caregivers. Further investigation into the relationship between family functioning and perceived support is needed.

## Caregiver Age

The control variable of caregiver age was included in the discriminant analysis because it may a significant independent distinction between caregivers who viewed family support as adequate and those who viewed family support as less than adequate. The variable of age has been found to correlate with perceived support.

One of the possible explanations that age influences perceived support is the association of age with relationship to the ill relative. Caregivers who are spouses tend to be older than caregivers who are adult children. The intimacy and obligation of a marital relationship promotes a view that spouses will care for each other with little assistance from others (Colerick and George, 1986). If an older spouse caregiver believes that he or she should do most of the caregiving, even small amounts of help from other family members may be deemed as adequate support. On the other hand, filial obligation for children to care for an elderly, ill parent may prompt a younger adult child caregiver to expect help from other family members, particularly siblings (Lerner, et al., 1991). If the siblings are not providing their "share" of the caregiving duties, or providing emotional help, the caregiver may view family support to be less than adequate. Therefore, the relationship between age and perceived family support may be mediated by expectations for family help. This variable may require further investigation to clarify its relationship with perceived support.

Caregiver Gender

This control variable was not included in the discriminant analysis because it did not make a significant independent separation between the two groups of caregivers. Although evidence from the literature suggests that there may be a connection between gender and perceived support (Antonnucci & Akiyama, 1991; McFarlane, et al., 1983, 1984; Stolar, MacEntee & Hill, 1993; Wethington & Kessler, 1986), this relationship was not found in the present study.

One possible explanation for the lack of effect of gender in the analysis may be that the number of males in the study was very small. Males accounted for 18% of the sample. It is possible than the number of males in the sample did not carry enough weight for gender to distinguish between caregivers who viewed family support to be adequate and those who viewed family support to be less than adequate.

## Years of Education

The control variable of years of education was not included in the discriminant analysis because it was not significant in univariate analysis. Studies in the literature suggested that years of education may influence perceived support (Kosberg, et al., 1990; McFarlane, et al., 1983; Wethington & Kessler, 1986). However, results of this study did not suggest the same conclusion.

One possible explanation may be that the majority of caregivers in the sample were highly educated, with some post-secondary education. The small variance in years of education within the sample may have reduced its influence on perceived support. Another possible explanation may be that perceptions of family support, based on family characteristics, are biased by societal norms and family history and obligations which affect all people in that society, regardless of years of education. Perceived support may not be a matter of formal education, but of informal education through experience.

## Predictors of Perceived Family Support

The combination of four family network characteristics and age as a discriminant function accounted for 23% of the variance between the two groups of caregivers. This would indicate that family network characteristics and age make a significant contribution to perceived family support. Researchers have been studying the link between network characteristics (eg. structure, behaviour) and perceived support for a number of years (Cutrona, 1986; Stokes, 1983; Vaux & Athanassopulou, 1987). Evidence from the present study and the literature suggests that network characteristics do influence perceived support. However, the relationship is complex and requires further investigation (Vaux & Athanassopulou, 1987).

Part of the complexity of the relationship between network characteristics and perceived support may be the influence of other variables. Within an ecological perspective, one small set of family network characteristics was not expected to account for all of the variance between the two groups of caregivers.

Evidence for this was the significance of caregiver age in discriminating between the two groups of caregivers.

According to the conceptual framework of social support and the coping process portrayed in Figure 1 (Heller & Swindle, 1983) there may be variables other than family network characteristics contributing to the perception of family support. For example, friend and professional networks may also influence perceived support. It is possible that help or interactions with friends or formal sources (eg. counsellors, nurses, etc.) may influence how the family relationships are viewed. For example, if some of the needs created by the situation are attended to by non-family members, the help the family members provide for other needs by be viewed as adequate by the caregiver. A study of spouse caregivers for Alzheimer's patients by Borden (1991) produced some evidence for a relationship between perceived friend support and perceived family support. Non-family relationships should also be considered when examining perceived family support.

Also part of Heller and Swindle's (1983) model is the influence of person characteristics on perceived support. Person characteristics were referred to as "assets" which help to establish and maintain network connections (eg. communication skill, attractiveness, etc.). Person characteristics may also include locus of control, independence, self-confidence, age, gender, etc. which could impact upon an individual's perceived support. For example, a person who is very dependent upon others may view five contacts a week with family members as less than adequate support while an independent individual may view five contacts as very supportive. Person characteristics may be included in the list of possible predictors of perceived family support.

In summary, family network characteristics explained part of the differentiation between caregivers who viewed family support as adequate and those who did not. However, there may be other variables, such as non-family connections, person characteristics and demographic information which may also help to

distinguish between caregivers who perceive family support to be adequate and those who perceive family support to be less than adequate.

## Implications and Future Directions

The results of this study have implications for both theory and practice. With regard to theories of social support, researchers need to be cautious when assuming that certain relationships or behaviors are supportive for people in stressful situations, such as caregivers of Alzheimer's patients. Not all family network characteristics should be assumed to indicate that the caregiver feels supported. Subjective perceptions of support also need to be included within studies of social support.

With regard to practice, determining the family network characteristics which best discriminate between caregivers who feel supported by other family members and those who do not, could have implications for health professionals working with caregivers of relatives with Alzheimer's disease. There seems to be a view within the helping professions that if resources, such as family members, can be mobilized to assist the caregiver, the caregiver will feel supported and will be able to care for her or his relative in the community for a longer period of time before seeking institutional care. Knowing what family characteristics to look for in determining which caregivers may be receiving adequate family support and those who may need further intervention could assist professionals in the health and welfare realms in better servicing caregivers. For example, caregivers at risk for feeling unsupported could be identified and assisted through formal interactions. In addition, asking the caregiver about his or her support is also an important aspect of assessment because it is subjective cognitive appraisal which ultimately affects the caregivers actions. (See Figure 1 for the theoretical model verifying this statement.) In addition, it is important for practitioners to remembers that variables other than family characteristics (eg. caregiver age) may influence perceived support.

As evidence accumulates linking family network characteristics to perceived family support, several issues arise for future research. Perceived support is a

complex construct. When asking caregivers whether the support they receive is adequate for their needs, how are they conceptualizing support? Are the caregivers considering the amount of help they receive, their satisfaction with the help they receive or their beliefs about the support they should receive as compared to what they are receiving (Procidano & Heller, 1983; Vaux & Athanassopulou, 1987)? Future research may incorporate more comprehensive and tested measures of perceived support as well as a global measure, such as the one used in the present study.

Finally, there are many variables which may influence perceived support. The inclusion or control of various person characteristics may help to distinguish between caregivers who feel supported and those who do not (Heller & Swindle, 1983). The role of other network members, such as friends or professionals, may also influence perceived family support (Borden, 1991). It is important for researchers and practitioners to recognize that there are multiple variables affecting perceived support.

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# APPENDIX A

## Questionnaire Items and Family Trees

### Independent Variables

Frequency of Contact

**Frequency of contact provided by family members**

1. Please estimate how many times in the past week you have had contact (either telephone, letter or face-to-face) with family members, either related to care of your relative, or for other reasons.

| Name or initials | Relation | Frequency of Contact in the past week | How many of these times was the contact related to your ill relative |
|---|---|---|---|
| ____ | _____ | _____ | _____ |
| ____ | _____ | _____ | _____ |
| ____ | _____ | _____ | _____ |
| ____ | _____ | _____ | _____ |
| ____ | _____ | _____ | _____ |
| ____ | _____ | _____ | _____ |
| ____ | _____ | _____ | _____ |
| ____ | _____ | _____ | _____ |

Family Network Size

## Family Tree
## for Caregivers who are Spouses of the Ill Relative

| GENERATION #1 | GENERATION #2 | GENERATION #3 |
|---|---|---|
| Name_____ A___ D___ G___ (Siblings of caregiver) | Name_____ A___ D___ G___ (Children of caregiver) | Name_____ A___ D___ G___ (Grandchildren of caregiver) |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ (Caregiver) | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ (Spouse of caregiver) | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ (Siblings of spouse) | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |

KEY: A=age in years
D=distance living from caregiver
G=gender

# Family Tree

## for Caregivers who are Children of the Ill Relative

| GENERATION #1 | GENERATION #2 | GENERATION #3 |
|---|---|---|
| Name_____ A___ D___ G___ (Maternal aunts/uncles of caregiver) | Name_____ A___ D___ G___ (Siblings of caregiver) | Name_____ A___ D___ G___ (Children of caregiver) |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A ___ (Mother of Caregiver) | **Name**_____ A___ D___ G___ (Caregiver) | Name_____ A___ D___ G___ |
| Name_____ A ___ (Father of caregiver) | **Name**_____ A___ D___ G___ (Spouse of caregiver) | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ (Paternal aunts/uncles of caregiver) | Name_____ A___ D___ G___ (Spouse's siblings) | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |
| Name_____ A___ D___ G___ | Name_____ A___ D___ G___ | Name_____ A___ D___ G___ |

KEY: A=age in years D=distance living from caregiver G=gender

** A fourth generation was added to include these caregiver's grandchildren.**
** Family trees for other caregivers (eg. grandchild caregivers) were adjusted accordingly.**

SOCIAL RELATIONSHIP SCALE:

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Pages 69 & 70

Number of Family Members Providing Help Specific to Caregiving

## Family Members Providing Support Related to Caregiving

Please list the people with whom you generally discuss your ill relative (other than professionals), using the first name or initials only. After each name or set of initials, fill in a one- or two-word description of the relation each person has to you (i.e. brother, mother, sister). Then go on to check the box which indicates the degree of helpfulness or unhelpfulness of your discussions with each person. Do not feel you have to fill up all the spaces provided.

| **Name or initials** | **Relation** | **Helpfulness of discussion** *(Check one box)* | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | makes things a lot worse | makes things a bit worse | | helps things a bit | | helps things a lot | |
| ____ | _____ | o | o | o | o | o | o | o |
| ____ | _____ | o | o | o | o | o | o | o |
| ____ | _____ | o | o | o | o | o | o | o |
| ____ | _____ | o | o | o | o | o | o | o |
| ____ | _____ | o | o | o | o | o | o | o |
| ____ | _____ | o | o | o | o | o | o | o |
| ____ | _____ | o | o | o | o | o | o | o |
| ____ | _____ | o | o | o | o | o | o | o |

Practical Help and Emotional Help Received

## Help Provided by Family Members

Part A. Please indicate whether you receive each of the following types of help in caring for your relative from other family members by checking off either yes or no. If yes, please indicate this person's relation to you.

| | | Relationship (i.e. sister, brother, mother, son, etc.) |
|---|---|---|
| Arranging appointments: | Yes ___ No ___ | _____ |
| Providing respite care: | Yes ___ No ___ | _____ |
| Accompanying relative/caregiver on outings: | Yes ___ No ___ | _____ |
| Providing domestic help: | Yes ___ No ___ | _____ |
| Providing physical care: | Yes ___ No ___ | _____ |
| Providing entertainment: | Yes ___ No ___ | _____ |
| Handling business/legal affairs: | Yes ___ No ___ | _____ |
| Providing financial assistance: | Yes ___ No ___ | _____ |
| Visiting relative during temporary hospital stay: | Yes ___ No ___ | _____ |
| Providing transportation | Yes___ No___ | _____ |
| Providing relative/caregiver with a place to stay | Yes___ No___ | _____ |
| Lending or giving something other than money | Yes___ No___ | _____ |
| Providing comfort through (using) physical affection | Yes___ No___ | _____ |

Part B. Please indicate whether you receive each of the following types of emotional support in caring for your relative from other family members by checking off either yes or no. If yes, please indicate this person's relation to you.

| | | Relationship (i.e. sister, brother, mother, son, etc.) |
|---|---|---|
| Advice/Information/Guidance | Yes___ No___ | _____ |
| Present (there for you physically) in a stressful situation | Yes___ No___ | _____ |
| Reassuring you that you are OK just the way you are | Yes___ No___ | _____ |
| Comforting you by showing you physical affection | Yes___ No___ | _____ |
| Listening to you talk about your private feelings | Yes___ No___ | _____ |

| | | Relationship (i.e. sister, brother, mother, etc.) |
|---|---|---|
| Telling you that they feel very close to you | Yes____ No____ | _____ |
| Joking and using humor to try to cheer you up | Yes____ No____ | _____ |
| Expressing interest and concern in your well-being | Yes____ No____ | _____ |
| Going with you to see someone who helped you with a problem you were having | Yes____ No____ | _____ |
| Telling you they would keep the things you talked about privately just between the two of you | Yes____ No____ | _____ |
| Doing activities with you to help get your mind off things | Yes____ No____ | _____ |
| Telling you how they felt in a situation that was similar to yours | Yes____ No____ | _____ |
| Others (specify): | Yes____ No____ | _____ |

FAMILY RELATIONSHIPS:

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Pages 74 & 75.

Months Since Diagnosis

When was your relative diagnosed? _____ months

**Control Variables**

Age of Caregiver

Caregiver's age: _____

Gender of Caregiver

Caregiver's gender: _____

Years of Education

Number of years of formal education: _____

**Dependent Variable**

Adequacy of Family Support

1. How adequate to your needs is the balance of support your family provides?

More than adequate ___ Adequate enough ___ Less than adequate ___

Explain: _____

_____

# APPENDIX B

## Sample Size Calculation

Sample size calculation for multiple variables:

$$n = L/.25 + k + 1$$

where k = number of variables and L = 16.80 for alpha = .05

$$n = 16.80/.25 + 11 + 1$$

$$n = 79.2$$

therefore, minimum sample size is 79 subjects.